General

Guideline Title

NHF-McMaster guideline on care models for haemophilia management.

Bibliographic Source(s)

Pai M, Key NS, Skinner M, Curtis R, Feinstein M, Kessler C, Lane SJ, Makris M, Riker E, Santesso N, Soucie JM, Yeung CHT, Iorio A, SchÃ¼nemann HJ. NHF-McMaster guideline on care models for haemophilia management. Haemophilia. 2016 Jul;22 Suppl 3:6-16. [34 references] PubMed

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Recommendations

Major Recommendations

The rating schemes for the quality/certainty of the evidence (high certainty, moderate certainty, low certainty, very low certainty) and the strength of the recommendations (strong, conditional) are defined at the end of the "Major Recommendations" field.

Question 1

Should integrated care vs. non-integrated care be used for people with haemophilia?

Recommendation: For persons with haemophilia, the Guideline Panel suggests that the integrated care model be used over non-integrated care models (conditional recommendation, moderate certainty in the evidence).

Recommendation: For persons with haemophilia with inhibitors, and those at high risk for inhibitor development, the Guideline Panel recommends that the integrated care model be used over non-integrated care models (strong recommendation, moderate certainty in the evidence).

Question 2

For individuals with haemophilia, should a haematologist, a specialized haemophilia nurse, a physical therapist, a social worker or round-the-clock access to a specialized coagulation laboratory be part of the integrated care team, vs. an integrated care team with a lesser complement?

Recommendation: For individuals with haemophilia, the Panel suggests that a hematologist, a specialized haemophilia nurse, a physical therapist, a social worker, and round-the-clock access to a specialized coagulation laboratory be part of the integrated care team, over an integrated care team that does not include all of these components (conditional recommendation, very low certainty in the evidence).

Definitions

Grading of Recommendations Assessment, Development and Evaluation (GRADE) Working Group Grades of Evidence

The GRADE working group defines the certainty of evidence as the extent of confidence that the estimate of an effect is adequate to support a particular decision or recommendation. The overall certainty of the evidence was assessed for each outcome using the GRADE approach for each important outcome, and expressed using four (i.e., high, moderate, low, very low) categories.

Strength of Recommendations

The GRADE working group defines the strength of a recommendation as the extent to which one can be confident that the recommendation's desirable effects outweigh its undesirable effects. That is, the recommendation to use a model of care, or include a health care professional on an integrated care team, should be based on the trade-offs between benefits on the one hand, and risks, burdens and costs on the other hand. If the benefits outweigh risks, burden and costs, experts will recommend that an intervention should be delivered. This is the *direction* of the recommendation. Meanwhile, the uncertainty associated with the trade-off between the benefits and risks and burdens will determine the *strength* of that recommendation. A recommendation can be either strong or conditional.

Strong Recommendation: The Panel had an option to grade recommendations as strong for or against the intervention when desirable effects were much greater than undesirable effects or vice versa. The implication of a strong recommendation for policy makers is that it can be adapted as a policy in most situations. For clinicians, most patients should receive the recommended course of action. For patients, a strong recommendation indicates a course of action that most patients would adopt and only a small proportion would not.

Conditional Recommendation: Recommendations were graded as conditional for or against the intervention when desirable effects were not clearly greater than undesirable effects or vice versa. A conditional recommendation indicates that policymaking will require a more substantial debate and involvement of many stakeholders. For clinicians, different choices will be appropriate for different patients. For patients, conditional recommendations suggest a course of action that many patients, but not all, would adopt.

Clinical Algorithm(s)

None provided

Scope

Disease/Condition(s)

Haemophilia

Guideline Category

Management

Clinical Specialty

Family Practice

Hematology

Internal Medicine

Pediatrics

Intended Users

Advanced Practice Nurses

Allied Health Personnel

Clinical Laboratory Personnel

Health Care Providers

Health Plans

Hospitals

Managed Care Organizations

Nurses

Other

Patients

Physical Therapists

Physician Assistants

Physicians

Public Health Departments

Social Workers

Guideline Objective(s)

- To identify best practices in haemophilia care delivery and discuss the range of care providers and services that are most important for persons with haemophilia (PWH) across the United States
- To support patient-centred clinical decision-making and optimize haemophilia care for each patient

Target Population

Persons living with haemophilia and providers of haemophilia care

Interventions and Practices Considered

1. Use of an integrated care model (versus non-integrated care model)
2. Composition of the integrated care team (range of care providers)

Major Outcomes Considered

- Mortality
- Missed days of school or work
- Number of emergency room visits
- Length of in-patient stay
- Quality of life
- Joint damage or disease
- Educational attainment
- Patient adherence
- Patient knowledge

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Searches of Unpublished Data

Description of Methods Used to Collect/Select the Evidence

Evidence Retrieval

The Core Methods Group used several methods to retrieve evidence to address the final guideline questions. For evidence on benefits and harms, systematic reviews of the literature and systematic observations were used. For evidence on patient values and preferences, acceptability, equity, feasibility and resource use, systematic reviews of the literature and both surveys of and structured qualitative interviews with key stakeholders were employed. An overview of the process is presented below; see the "Availability of Companion Documents" field for details, including search strategies.

Systematic Reviews

Systematic reviews of published literature were performed to retrieve evidence on the benefits and harms of different models of care delivery, patients' values and preferences, equity, acceptability, feasibility, costs and resource use. Details of the search strategies and systematic review results for benefits and harms are provided in a companion paper by Yeung et al. (see the methodology companion in the "Availability of Companion Documents" field). In brief, for evidence on benefits and harms, the Core Methods Group searched OVID MEDLINE, OVID MEDLINE In-Process and Other Non-Indexed Citations, OVID EMBASE, EBSCO Cumulative Index to Nursing & Allied Health Literature (CINAHL) up to April 22, 2015. The search was not restricted by language or study design. Additional studies were identified by searching reference lists of retrieved papers (snowball search), searching Cochrane reviews, and contacting Panel Members and other clinical experts in the field. Two trained investigators independently screened title, abstract, and full text of relevant articles for inclusion. A third trained investigator adjudicated all disagreements. Authors of abstracts of meeting proceedings that were retrieved from the search were contacted by e-mail to inquire about the availability of a subsequent full text. Any article that focused on a model of care delivery, and compared outcomes in: people who received one model of care versus people who received at least one other model of care; people before and after receiving a single model of care; people who had received services from a health care professional/specialized coagulation laboratory in the integrated care setting versus people who had not received services from that health care professional/specialized coagulation laboratory; or described a single model of care without any comparisons was included. Included studies must have reported at least one of the nine outcomes of interest.

It was anticipated that there would be limited published evidence on the impact of different care models in the management of haemophilia, as a combined consequence of the rarity of the disease and overall paucity of randomized controlled trials in the area of assessment of complex public health interventions. To retrieve as much relevant evidence as possible, the Guideline Panel performed an ancillary systematic search for evidence about models of care in the field of chronic diseases. Through the search, they were able to retrieve a meta-review on integrated care programmes for adults with chronic conditions. The diseases covered by the meta-review that were relevant to the present guideline were congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD) and asthma. These diseases shared some features with haemophilia: chronicity, high resource use, involvement over the life span (for asthma) and delivery of care via multidisciplinary integrated models. Therefore, they were selected to be considered by the Panel as a well-developed body of literature that discussed care models. An updated search of the meta-review was performed and quality evidence was assessed by the Core Methods Group.

At the screening stage of the systematic review of the haemophilia literature, any study that addressed patient values and preferences, acceptability, feasibility, equity or resource use were flagged for inclusion in the *ad hoc* body of evidence.

Systematic Observations

The search for evidence was hampered by a dearth of comparative studies – particularly for question 2 (For individuals with haemophilia, should a hematologist, a specialized haemophilia nurse, a social worker, or round-the-clock access to a specialized coagulation laboratory be part of the

integrated care team, versus an integrated care team with a lesser complement?). In the past, guidelines were often based on expert opinion, in absence of published evidence. Recognizing the limitations of such an approach and building on previous experience, the Guideline Panel adopted a more systematic and structured approach to seeking evidence in absence of published literature. They set out to systematically capture clinical observations from the Guideline Panel, as well as a selection of other individuals identified as experts in the field using a standardized approach. Respondents were asked to fill out a specifically designed form (see Appendix S1 in the guideline methodology companion), aiming to collect objective information that they could attest to, supported by unpublished data and/or their own observations. In this regard, particular attention was devoted to collect direct experiential data useful for judgement, rather than 'second hand' expert opinions based on low-quality publications or common practice. This information was collated and presented to the Guideline Panel at the second face-to-face Panel meeting, as part of the evidence base to be used for making recommendations.

Qualitative Interviews with Key Stakeholders

It was anticipated that there would be little data for health and psychosocial outcomes important to key stakeholders; acceptability of different models of care to key stakeholders; impact of different models of care on health inequities; and feasibility of implementing different models of care. Therefore, a qualitative study was undertaken to address these anticipated evidence gaps. A complete description of the study design, methodology and study strengths and limitations is reported in a companion paper by Lane et al. (see the "Availability of Companion Documents" field). The study results were synthesized and presented to the Guideline Panel at the second face-to-face Panel meeting, as part of the evidence base to be used for making recommendations.

Refer to the "Results" sections and Figure 1 in the guideline and the systematic review (see the "Availability of Companion Documents" field) for a detailed discussion of the results of the literature search.

Number of Source Documents

Question 1

Twenty-seven unique non-randomized studies (which were reported in 32 published articles) were included in the review. Eight studies were comparative and 19 studies were single-arm non-comparative studies.

Question 2

There were no randomized controlled trials or nonrandomized studies. Two databases originated by survey studies provided data on access to health care professionals within a Haemophilia Treatment Centre. There is also indirect evidence from two systematic reviews in people with haemophilia. Finally, structured experiential data were systematically gathered from individuals on the Panel.

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Quality Grading

The Grading of Recommendations Assessment, Development and Evaluation (GRADE) working group defines the certainty of evidence as the extent of confidence that the estimate of an effect is adequate to support a particular decision or recommendation. The overall certainty of the evidence was assessed for each outcome using the GRADE approach for each important outcome, and expressed using four (i.e., high, moderate, low, very low) categories.

Methods Used to Analyze the Evidence

Review of Published Meta-Analyses

Systematic Review with Evidence Tables

Description of the Methods Used to Analyze the Evidence

Evidence Synthesis

Details of eligible studies and systematic reviews were abstracted and synthesized quantitatively (whenever possible) or narratively. Data for patient values and preferences, acceptability, feasibility and equity issues were narratively pooled. The results from comparative studies were presented in evidence profiles (EPs) using the GRADEproGDT software and the standard Grading of Recommendations Assessment, Development and Evaluation (GRADE) methodology. Separate EPs were also created to describe the results of the non-comparative non-randomized studies, using the format provided in GRADEproGDT for prognostic evidence (single-arm non-comparative cohorts).

Both the effects of the models of care on each outcome and the certainty of the evidence were presented in the EPs.

Pre-assessment of Indirectness for Evidence on Chronic Diseases

In the GRADE approach, 'direct' evidence consists of research that directly compares the interventions that the Guideline Panel are interested in, is delivered to the populations they are interested in, and measures outcomes that are important to patients. Judgment of directness is done as part of preparing an EP. However, the Core Methods Group considered the judgment of directness for a body of evidence known to be focusing on an intentionally different set of diseases as one requiring a specific and more detailed approach. Using the form in online Appendix S2 of the original guideline document, the Panel was asked before the Panel meeting to judge whether this evidence was 'direct enough' to draw parallels to haemophilia, and could inform the care of persons with haemophilia (PWH). Ratings of directness were solicited for each outcome, for each study in other chronic diseases proposed to be used in the guideline process. Based on their summated responses, assessments of indirectness were incorporated into the EPs.

Evidence to Decision (EtD) Framework

One of the most critical steps of the guideline development process is moving from evidence appraisal to issuing recommendations. The GRADE methodology is particularly aware of the importance of maximizing transparency of this step, which is accomplished by guiding and tracking the entire panel discussion using a specific template called EtD framework. For both guideline questions, EtDs were developed following the GRADE approach. Information about benefits and harms, patient values and preferences, resources, acceptability, feasibility, and equity issues from the systematic review were summarized in each EtD, and circulated to the Guideline Panel in advance of the Panel meeting together the respective EP.

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

Guideline Process

In 2013, the National Hemophilia Foundation (NHF) brought together a small committee to determine the priority topics for guideline development in haemophilia. This committee was composed of current and past chairs of the NHF's Medical and Scientific Advisory Council (MASAC), members of the World Federation of Haemophilia (WFH) guideline Panel and several NHF staff members and Consultants. High-priority topics were identified as areas of clinical practice undergoing change, that are subject to uncertainty, that present challenges with access to care, or that are subject to geographic practice variations. From a short list of priority topics, the committee recommended to the NHF that the first topic to address in a clinical practice guideline (CPG) be models of haemophilia care delivery. The key steps followed to develop the guideline are summarized and described below. There were three principal groups involved in the guideline development process: the Consultants based at the NHF who coordinated the logistics of the guideline development process, the Core Methods Group of Consultants based at McMaster University who conducted the methodologic work, and the Guideline Panel described below.

Selection of Guideline Panel

The NHF and Core Methods Group generated a short list of potential Panel members. Criteria for selection included an established personal, clinical and/or research record in haemophilia or rare diseases, balanced gender representation, and an absence of conflicts of interest (COIs) that were judged unacceptable. Invited participants were under no obligation to participate. Two co-chairs of the Panel were chosen: a clinical co-chair who is a leader in haemophilia research and practice, and a methodological chair who had extensive previous experience leading guideline panels and expertise in guideline methodology. All Panel members participated in the entire guideline process via teleconferences, electronic communications, surveys and two in-person meetings. Short training videos were distributed to the Panel to prepare members for the decision-

making process.

Question Development and Refinement

Key stakeholders were surveyed to generate a list of specific questions and outcomes to be addressed within the scope of the guideline and serve as the basis for the guideline's recommendations.

A survey was distributed by email to MASAC members, US Haemophilia Treatment Centre (HTC) staff (from a public mailing list on the Centers for Disease Control Web site), NHF Chapter Presidents, and members of the NHF Nursing, Physical Therapy and Social Work Working Groups. Recipients were asked to provide feedback about questions in practice concerning different models of care and important considerations with groups of persons with haemophilia (PWH) (e.g., people with severe, moderate or mild haemophilia). They were also asked to propose, review, and rate the importance of health system and patient outcomes on a scale from 1 (least important) to 9 (most important). Over 200 responses were received, the results were compiled, and the average rating of the questions and outcomes were calculated. Any textual comments provided were compiled in a summary document. This feedback was circulated to the Guideline Panel and discussed during the first face-to-face Guideline Panel Meeting, held in Milwaukee in June 2014. During this meeting, the Panel generated the final questions to address in the CPG; prioritized the sub-populations of PWH to address in the CPG; and selected the outcomes critical to consider when ultimately making the recommendations.

Finally, two areas were identified by the NHF and McMaster University working group as central to discussions around models of haemophilia care: the impact of different models of care, including the integrated care model typified by US HTCs, on patient-important outcomes; and the facets of the integrated care model necessary to produce improved patient-important outcomes.

The Panel was invited to frame the guideline questions in the PICO (patient-intervention-comparator-outcome) format. This format, commonly used in the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) system, ensures that questions – and subsequent CPG recommendations – are systematic, focused and practicable. The Panel formulated the two questions subsequently addressed by the CPG and a short list of relevant outcomes.

Formulating Recommendations

A face-to-face two-day meeting of the Guideline Panel was held in Chicago in May 2015 to formulate the final recommendations. Panel members introduced themselves and presented COIs verbally and in writing. COIs of all Panel members were managed in adherence to Institute of Medicine (IOM) recommendations. GRADE's Evidence to Decision (EtD) frameworks were used to guide a structured consensus process and transparently document all decisions made during the meeting. The formulation of recommendations considered the balance between the desirable and undesirable consequences of an intervention; the certainty of evidence; the variability in patient values and preferences; equity; acceptability; feasibility; and resource use issues.

The GRADE working group defines the strength of a recommendation as the extent to which one can be confident that its desirable effects outweigh its undesirable effects (see the "Rating Scheme for the Strength of the Recommendations" field for definitions).

Additional considerations around research, implementation, and monitoring were also discussed. The Core Methods Group recorded the Panel's discussions and decisions, ultimately creating a final unabridged Guideline Report for their approval, to be published in full and submitted to the National Guideline Clearinghouse.

Rating Scheme for the Strength of the Recommendations

Strength of Recommendations

The GRADE working group defines the strength of a recommendation as the extent to which one can be confident that the recommendation's desirable effects outweigh its undesirable effects. That is, the recommendation to use a model of care, or include a health care professional on an integrated care team, should be based on the trade-offs between benefits on the one hand, and risks, burdens and costs on the other hand. If the benefits outweigh risks, burden and costs, experts will recommend that an intervention should be delivered. This is the *direction* of the recommendation. Meanwhile, the uncertainty associated with the trade-off between the benefits and risks and burdens will determine the *strength* of that recommendation. A recommendation can be either strong or conditional.

Strong Recommendation: The Panel had an option to grade recommendations as strong for or against the intervention when desirable effects were much greater than undesirable effects or vice versa. The implication of a strong recommendation for policy makers is that it can be adapted as a policy in most situations. For clinicians, most patients should receive the recommended course of action. For patients, a strong recommendation indicates a course of action that most patients would adopt and only a small proportion would not.

Conditional Recommendation: Recommendations were graded as conditional for or against the intervention when desirable effects were not clearly greater than undesirable effects or vice versa. A conditional recommendation indicates that policymaking will require a more substantial debate and involvement of many stakeholders. For clinicians, different choices will be appropriate for different patients. For patients, conditional recommendations suggest a course of action that many patients, but not all, would adopt.

Cost Analysis

A formal cost analysis was not performed and published cost analyses were not reviewed.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

After final review of the unabridged Guideline Report by the Panel Members, the guidelines were presented to the public at a meeting of the Medical and Scientific Advisory Council (MASAC), held at the National Hemophilia Foundation's 2015 Annual Meeting in August 2015. All stakeholders (including members of the public) were invited to this open meeting, and were invited to review the Guideline Report and submit comments electronically during a subsequent six-week public review period. The Core Methods Group reviewed all comments and incorporated them into the Guideline Report where possible. However, no change to the core recommendations or assessments of the quality of the evidence was made, nor were any *a priori* decisions regarding methodology.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of supporting evidence is identified and graded for each recommendation (see the "Major Recommendations" field).

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

The systematic review for this guideline found low- to very low-quality evidence that integrated care reduces mortality, emergency room and walk-in clinic visits, hospitalizations (and length of stay), missed days of school and work, and increases knowledge seeking. The evidence for the effects of integrated care on functional status, measured by joint damage or joint disease was less clear, and the analysis is likely confounded by disease severity.

The balance of potential benefits and harms for individual recommendations was considered and is discussed further in the original guideline document.

Potential Harms

The balance of potential benefits and harms for each recommendation was considered and is discussed in the original guideline document.

Qualifying Statements

Qualifying Statements

- Although there was a limited amount of direct, high-quality evidence pertaining to models of care delivery in haemophilia, and a paucity of data addressing some patient-important outcomes, resource use, and impact on equity, feasibility and acceptability, the panel considered all of these factors to make recommendations based on the best available evidence to date. For this reason, the panel has supplemented its recommendations with clear suggestions to guide National Haemophilia Foundation (NHF) and the broader haemophilia community in setting research priorities to consolidate and expand the evidence base of these recommendations.
- The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Implementation of the Guideline

Description of Implementation Strategy

Implementation Considerations and Monitoring

Question 1: Should integrated care versus non-integrated care be used for people with haemophilia?

Patient access is vital to the success of the integrated care model. Access challenges could be addressed by telehealth, outreach clinics or hub and spoke strategies; these features (which were beyond the scope of the current guideline) could make the integrated care model more feasible. They merit further study. The Panel notes that access to care varies based on geographic location, race/ethnicity and insurance status. As part of the panel's recommendation for integrated care, it encourages individual integrated care centres and the US Haemophilia Treatment Centre (HTC) network to be mindful of access issues, and take steps to rigorously evaluate and address them. Integrated care centres must also optimize their capacity to care for persons with haemophilia (PWH). The Panel cited that stable funding for integrated care centres might improve capacity, overall implementability and outcomes.

The Panel acknowledges that PWH may also access care differently based on their unique characteristics. For example, the frequency of visits may depend on the severity of disease, and PWH may need different components of the integrated care at different times. Age may also affect the frequency of visits in an inverse fashion (e.g., with paediatric patients seen more frequently). Integrated care must reflect this diversity of patient needs. Further, circumstances may dictate that PWH seek care from different integrated care centres, or different settings, as not all integrated care centres are equivalent. For example, female carriers, who often exhibit a mild bleeding phenotype, may prefer HTCs that offer specialized obstetric/gynaecologic care. It is of primary importance that the care of patients with haemophilia must be guided by individuals with sufficient clinical expertise.

Finally, the Panel highlights the importance of unified data systems in US HTCs, to facilitate dynamic ongoing monitoring of models of care and their impact on patient-important outcomes.

Question 2: For individuals with haemophilia, should a haematologist, a specialized haemophilia nurse, a physical therapist, a social worker or round-the-clock access to a specialized coagulation laboratory be part of the integrated care team, vs. an integrated care team with a lesser complement?

Standardization is needed to define the components of the integrated care model, and lay out performance metrics (that take into consideration the impact of care on patient outcomes). These are currently lacking. The Panel advocates that integrated care models aim to standardize their different components of care to minimize practice variations. The standardization of these components, and their impact on patient-important outcomes, should be evaluated.

The Panel has made a recommendation on the minimum team cohort for integrated care centres – a physician, a nurse, a physical therapist, a social worker and a specialized coagulation laboratory. However, as noted above, PWH have unique needs and characteristics, so there may be situations where there is a need for additional health care providers or components of care. Demographic studies have confirmed that the natural history of haemophilia is changing. Moreover, the US health care system is also changing. Thus, it is important that integrated care centres respond to the needs of their patient population in a dynamic way, to ensure the long-term sustainability of these centres.

The Panel's recommendations around components of care refer to the current state of haemophilia care in the US; they acknowledge that the landscape of health care systems and insurance is changing rapidly. Integrated care centres and the larger haemophilia community must optimize their ability to train, recruit and retain specialized health care team members to meet the needs of PWH. This would ensure that all integrated care

centres have a standardized team of expert health care providers.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

Pai M, Key NS, Skinner M, Curtis R, Feinstein M, Kessler C, Lane SJ, Makris M, Riker E, Santesso N, Soucie JM, Yeung CHT, Iorio A, SchÃ¼nemann HJ. NHF-McMaster guideline on care models for haemophilia management. Haemophilia. 2016 Jul;22 Suppl 3:6-16. [34 references] PubMed

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2016 Jul

Guideline Developer(s)

McMaster University - Academic Institution

National Hemophilia Foundation - Nonprofit Organization

Source(s) of Funding

This work was funded by the National Hemophilia Foundation.

Guideline Committee

NHF-McMaster Guideline on Care Models for Haemophilia Management Guideline Panel

Composition of Group That Authored the Guideline

Panel Members: M. Pai, Department of Medicine; Department of Pathology and Molecular Medicine; McMaster Centre for Transfusion Research, McMaster University, Hamilton, ON, Canada; N. S. Key, Department of Medicine, University of North Carolina, Chapel Hill, NC; M. Skinner, Institute for Policy Advancement Ltd., Washington, DC; R. Curtis, Factor VIII Computing, Berkeley, CA; M. Feinstein, National Hemophilia Foundation, New York, NY; C. Kessler, Georgetown University, Washington, DC, USA; S. J. Lane, McMaster Centre for Transfusion Research, McMaster University, Hamilton, ON, Canada; M. Makris, Department of Infection, Immunity and Cardiovascular Disease, University of Sheffield, Sheffield, UK; E. Riker, National Hemophilia Foundation, New York, NY; N. Santesso, Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, ON, Canada; J. M. Soucie, Centers for Disease Control and Prevention, National Center for Birth Defects and Developmental Disabilities, Division of Blood Disorders, Atlanta, GA, USA; C. H. Yeung, Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, ON, Canada; A. Iorio, Department of Medicine, Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, ON, Canada; H. J. Schünemann, Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, ON, Canada

Financial Disclosures/Conflicts of Interest

Refer to the original guideline document for the policy on managing conflict of interest used for this guideline.

Disclosures

MF, EK, NS, MJS, CHTY and HJS have stated that they had no interests which might be perceived as posing a conflict or bias. MP has received honoraria for speaking engagements from Bayer; and consulting income from Bayer, BMS-Pfizer and Sanofi. MS has received consulting income from NHF; research funding (via NHF) from Biogen, SOBI, Baxter, Bayer and Novo-Nordisk; and receives care at a US HTC. NSK's institution has received research funding from Baxter; consulting income from Bayer and Novo Nordisk; and works at a US HTC. RC has received consulting income from Bayer and Red Chip Pharmacy; funding from the University of Southern California, Hemophilia Utilization Group Study (HUGS) and non-monetary research support from NHF, HUGS and Bayer; and receives care at a US HTC. CK has received consulting income from Alnylam, Bayer, Baxter, Grifols, NovoNordisk, Octapharma, Pfizer and Roche; research funding from Bayer, Grifols, Octapharma and NovoNordisk; non-monetary research support from Bayer, Baxter, Grifols, NovoNordisk, Octapharma and Pfizer; works at a US HTC; and directs a 340B Program. SJL has received consulting honoraria from Novo Nordisk; and honoraria for speaking engagements from Bayer and the Canadian Hemophilia Society. MM's institution has received project-based funding from Bayer, Biogen, Baxter, Biotest, BPL, CSL Behring, LFB, Grifols, Kedrion, Octapharma, Pfizer, SOBI/Biogen and NovoNordisk; works at a non-US HTC. AI has received consulting income from Bayer and Biogen Idec; research support from NovoNordisk, Biogen Idec and Pfizer; and works at a non-US HTC.

Guideline Endorser(s)

American Society of Hematology - Medical Specialty Society

International Society on Thrombosis and Haemostasis - Professional Association

World Federation of Hemophilia - Nonprofit Organization

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Guideline Availability

Available from the Haemophilia Web site .

Availability of Companion Documents

The following are available:

- Pai M, Santesso N, Yeung CHT, Lane SJ, Schünemann HJ, Iorio A. Methodology for the development of the NHF-McMaster Guideline on Care Models for Haemophilia Management. Haemophilia. 2016 Jul;22 Suppl 3:17-22. Available from the Haemophilia Web site .
- Yeung CHT, Santesso N, Pai M, Kessler C, Key N S, Makris M, Navarro-Ruan T, Soucie JM, Schünemann HJ, Iorio, A. Care models in the management of haemophilia: a systematic review. Haemophilia. 2016 Jul;22 Suppl 3:31-40. Available from the Haemophilia Web site .
- Lane SJ, Sholapur NS, Yeung CHT, Iorio A, Heddle NM, Sholzberg M, Pai M. Understanding stakeholder important outcomes and perceptions of equity, acceptability and feasibility of a care model for haemophilia management in the US: a qualitative study. Haemophilia. 2016 Jul;22 Suppl 3:23–30. Available from the Haemophilia Web site .
- Yeung CHT, Santesso N, Zeraatkar D, Wang A, Pai M, Sholzberg M, Schünemann HJ, Iorio A. Integrated multidisciplinary care for the management of chronic conditions in adults: an overview of reviews and an example of using indirect evidence to inform clinical practice recommendations in the field of rare diseases. Haemophilia. 2016 Jul;22 Suppl 3:41–50. Available from the Haemophilia Web site .

Patient Resources

None available

NGC Status

This NGC summary was completed by ECRI Institute on September 29, 2016. The information was verified by the guideline developer on October 21, 2016.

Copyright Statement

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